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Responsibility for follow-up during the diagnostic process in primary care:

a secondary analysis of International Cancer Benchmarking Partnership data

Abstract

Background

It is unclear to what extent primary care practitioners (PCPs) should retain responsibility for follow-up to ensure that patients are monitored until their symptoms or signs are explained.

Aim

To explore the extent to which PCPs retain responsibility for diagnostic follow-up actions across 11 international jurisdictions.

Design and setting

A secondary analysis of survey data from the International Cancer Benchmarking Partnership.

Method

The authors counted the proportion of 2879 PCPs who retained responsibility for each area of follow-up (appointments, test results, and non-attenders). Proportions were weighted by the sample size of each jurisdiction. Pooled estimates were obtained using a random-effects model, and UK estimates were compared with non-UK ones. Free-text responses were analysed to contextualise quantitative findings using a modified grounded theory approach.

Results

PCPs varied in their retention of responsibility for follow-up from 19% to 97% across jurisdictions and area of follow-up. Test reconciliation was inadequate in most jurisdictions. Significantly fewer UK PCPs retained responsibility for test result communication (73% versus 85%, $P=0.04$) and non-attender follow-up (78% versus 93%, $P<0.01$) compared with non-UK PCPs. PCPs have developed bespoke, inconsistent solutions to follow-up. In cases of greatest concern, 'double safety netting' is described, where both patient and PCP retain responsibility.

Conclusion

The degree to which PCPs retain responsibility for follow-up is dependent on their level of concern about the patient and their primary care system's properties. Integrated systems to support follow-up are at present underutilised, and research into their development, uptake, and effectiveness seems warranted.

Keywords

cancer; diagnosis; diagnostic errors; diagnostic safety; general practice; primary care; safety netting.

INTRODUCTION

In primary care, the evolving diagnostic process incorporates the patient-professional encounter, performance of diagnostic tests, follow-up and tracking of diagnostic information over time, communication and coordination of referrals, and patient behaviours, adherence, and engagement.¹ These elements need not all occur, may occur out of sequence, and may form part of a 'wait-and-see' strategy due to the low risk of serious disease in primary care.^{2,3} Diagnostic error, defined as the 'failure to establish an accurate and timely explanation of the patient's health problem or communicate that explanation to the patient'⁴ may occur at any point throughout this diagnostic process.^{4,5} Globally, cancer is one of three diagnostic groups that predominate diagnostic error reports from primary care.⁴ A primary care practitioner's (PCP) failure to order appropriate diagnostic tests, incorrect interpretation of test results, and the absence of an appropriate follow-up plan are common themes in these reports.⁶⁻⁸ Furthermore, minimising the time taken for test ordering, performance, interpretation, and communication in primary care is regarded as key to improving cancer outcomes by reducing the time to definitive diagnosis.^{9,10}

Safety netting is a diagnostic strategy used when necessary in primary care

to ensure that patients are monitored throughout the diagnostic process until their symptoms or signs are explained.¹¹ It is a construct that encompasses a broad range of behaviours, including doctor-patient communication, clinician responsibilities, and system factors.^{11,12} It is regarded as best practice to protect against an initially inaccurate working diagnosis, but there is an absence of evidence on how best to safety net,¹³ especially in patients with non-specific symptoms that could be caused by cancer.^{11,14} One area of uncertainty is to what extent patients should retain responsibility for follow-up actions before they are referred to specialist care.^{7,15,16} Patients may underestimate the significance of symptoms, hesitate to re-consult, be concerned about wasting the doctor's time, or be unaware of their responsibility to follow up investigations, sometimes wrongly assuming 'no news is good news'.¹⁷⁻²⁰ Opportunities to re-assess, communicate test results, or take appropriate action may be missed.¹⁵ One strategy, therefore, could be for PCPs to retain more responsibility for follow-up.

The International Cancer Benchmarking Partnership Module 3 (ICBP3) surveyed PCPs in 11 international jurisdictions with varying cancer survival between May 2012 and July 2013,¹⁰ and May to September 2014 in New Zealand,²¹ to understand variations

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How this fits in

It is unclear to what extent primary care practitioners (PCPs) retain responsibility for follow-up actions during the diagnostic process. The authors found international variation in how PCPs retain responsibility, dependent upon the structure of the primary healthcare system and the PCP's level of concern for their patient. Shared responsibility between patient and PCP, or 'double safety netting', requires further investigation as a strategy used in cases of greatest concern. Electronic health record-based systems to facilitate follow-up actions are underutilised at present, and research into their development and uptake seem warranted.

in primary care behaviour and practice.^{22–24} In the present study, the authors aimed to explore internationally the extent to which PCPs retain responsibility for diagnostic follow-up, by describing the follow-up actions reported by PCPs in the ICBP3 survey. The authors also considered the UK in comparison with the other jurisdictions, given the UK's relatively poor cancer outcomes.

METHOD

The development of the ICBP3 survey is described in detail elsewhere.^{10,23} First, direct questions enquired about primary care practice in general. Second, clinical vignettes described patients presenting to primary care with a combination of symptoms and signs, each with a known risk of cancer, to investigate what follow-up action PCPs would choose (Appendix 1).

Retaining responsibility

For this secondary analysis, the authors defined 'retaining responsibility for follow-up during the diagnostic process' as situations in which the PCPs organised the next stage of the diagnostic process without a reliance on the patient to take action. Responses were categorised as: appointment follow-up, test reconciliation (making sure tests ordered were performed and results reviewed), test result communication, and follow-up for patients who did not attend (DNAs).

The four direct questions pertinent to this analysis are shown in Tables 1 and 2, and responses that demonstrate that the PCP would retain responsibility are flagged. These responses were independently selected by two researchers, while a third moderated any disagreements over selection. For three of these questions, PCPs

could select more than one option, including a free-text option. Where appropriate, and if not already selected by the PCP, two researchers reclassified free-text responses into the pre-existing response categories.

During the vignettes, PCPs were asked to select one of five options about appointment follow-up if they chose not to order an investigation (Table 3). Of these, retaining responsibility included PCPs arranging an appointment with the patient that was to be kept irrespective of improvement or worsening, or arranging an appointment with the patient to be cancelled if better. If PCPs chose to order an investigation, they were asked to select one of five follow-up options to communicate the test results to the patient (Table 4). Of these, retaining responsibility included PCPs contacting the patient with all test results, or contacting the patient if results were abnormal.

Analysis

For each jurisdiction, the proportion of PCPs retaining responsibility in each direct question or vignette was weighted using the Freeman-Tukey double arcsine transformation, to allow for variation in sample sizes.²⁵ To identify factors that may contribute to the poorer cancer outcome observed in the UK, pooled estimates for the proportion of PCPs choosing to retain responsibility were compared for the three UK jurisdictions and their non-UK counterparts. A random-effects meta-analysis was performed using the metaprop command in Stata. Pooled estimates were calculated, their 95% Wald confidence intervals, the I^2 statistic for heterogeneity, and the test of significance for differences between the UK and non-UK pooled estimates.²⁵ A P -value of <0.05 was deemed statistically significant.

All free-text responses to the direct questions were analysed independently of the quantitative results, then used to contextualise the quantitative findings. The free-text data were translated and analysed thematically by employing a modified grounded theory approach by two clinical researchers.²⁶ One of the researchers developed a coding scheme based on the content of the free-text responses, and grouped codes into themes. The other independently coded the free-text responses, which confirmed and expanded the coding scheme. Data saturation was reached, and quality and rigour were further improved by discussing the coding scheme and emerging themes in relation to the quantitative outcomes. Analysis was facilitated by NVivo 10.

Table 1. Proportion (%) of 2879 PCPs responding to four direct questions about follow-up, by jurisdiction

	UK				Non-UK						
					Europe			Canada		Australasia	
	Wales	NI	Engl	Den	Nor	Swe	Man	Ont	NSW	Vic	NZ
Total respondents, <i>n</i>	226	161	252	257	230	199	228	613	277	203	233
Follow-up appointments: 'If you want a patient to return for a follow-up appointment, how do you book this appointment?'											
Arrange the appointment at the time of the first appointment, % ^a	42	52	41	80	89	93	50	43	27	28	29
Ask the patient to book the appointment at the time of the first appointment, %	59	46	65	42	20	13	54	57	78	82	64
Ask the patient to book nearer to the proposed time of the follow-up appointment, %	28	23	19	13	12	7	14	14	9	9	17
Leave it to the patient's discretion, %	9	11	9	1	1	3	6	9	4	2	11
Other, %	10	6	7	3	3	9	6	6	5	3	7
Test reconciliation: 'What system do you have to ensure that you receive the result of every test/investigation you order?'											
No system, %	19	18	18	23	35	9	23	24	12	15	15
Automatically or manually record every test that is ordered and reconcile every test when the result is received, % ^a	27	33	23	25	29	69	39	19	53	45	38
Automatically or manually record some tests that are ordered and reconcile them when the results are received, %	22	20	21	26	24	14	21	36	23	28	40
Rely on patient to call or make an appointment for result, %	31	31	37	46	14	4	24	29	17	17	10
Other, %	18	14	18	17	11	12	11	12	10	6	9
Test communication: 'What do you normally do to ensure that all tests/investigation results are followed up?'											
No system, %	1	1	2	4	0	1	2	2	0	0	3
I receive the results and follow up at my discretion, % ^a	65	61	65	61	70	74	68	74	64	67	75
I ask the patient to call or make an appointment for the result, %	54	55	60	60	16	7	37	38	54	62	20
I tell the patient I will contact them only if the result is abnormal, % ^a	22	22	24	15	64	34	52	45	28	25	46
Other, %	14	8	4	19	8	25	9	8	11	8	10
Follow-up of non-attenders: 'If patients do not attend for scheduled follow-up appointments, do you contact them?'											
Yes, routinely, % ^a	6	6	6	11	15	23	17	21	35	25	23
Yes, selectively, % ^a	70	65	79	79	78	70	73	70	61	72	73
No, %	24	30	14	10	7	8	11	8	4	3	5

^aPCP retaining responsibility. Den = Denmark. Engl = England. Man = Manitoba. NI = Northern Ireland. Nor = Norway. NSW = New South Wales. NZ = New Zealand. Ont = Ontario. PCP = primary care practitioner. Swe = Sweden. Vic = Victoria.

RESULTS

A total of 2879 PCPs from 11 jurisdictions (nine countries) completed the survey. The crude response rate for the main ICBP3 survey was 12% (jurisdiction-specific response rates are reported elsewhere).¹⁰

Follow-up appointment

There was wide variation in the degree to which PCPs retained responsibility for appointment follow-up across jurisdictions, ranging from 27% (New South Wales) to 93% (Sweden). There was no statistically significant difference between UK and non-UK jurisdictions (45% versus 57%, $P = 0.27$). However, more European PCPs (80–93%) retained responsibility than the UK PCPs (41–52%) (Table 2). In the vignettes, UK PCPs retained responsibility less for appointment follow-up when no test was requested, but the difference was significant only in lung cancer vignette 4 (35% versus 58%, $P < 0.001$) (Table 3).

From the qualitative analysis (coding themes shown in Box 1), the authors found that PCPs titrated their retention of responsibility to their level of concern:

'Depends on my level of concern. If concerned about patient, will book follow-up when they are there for appointment. If less concerned, may tell them to call if no resolution in symptoms.' (PCP, Ontario)

And, if they were concerned about a potential cancer diagnosis (or other serious pathology), they would arrange follow-up at the time of the first appointment:

'If high index of suspicion of serious pathology, I will book the follow-up. At other times, I will ask the patient to go to reception and specify an interval for follow-up' (PCP, Wales)

Patient reliability, general frailty, or vulnerability also led some PCPs to book follow-up appointments directly. A barrier to this was a restricted number of appointments that PCPs could book directly. In less concerning situations, PCPs often delegated responsibility to patients with specific instructions:

'I give the patient a little note with the date I want to see the patient again. Then he gives it to my receptionist and gets an appointment. In that way, I save my time and the patient gets the most appropriate time.' (PCP, Denmark)

Some PCPs used easy-access 'walk-in' systems or 'open surgeries' to safety net,

which relied on patients taking responsibility to return.

Test reconciliation

There was wide variation in the PCPs retaining responsibility for reconciliation of test results, ranging from 19% (Ontario) to 69% (Sweden) (Table 1). Fewer UK PCPs tended to do this overall compared with non-UK PCPs (27% versus 39%, $P = 0.07$) (Table 2). Reconciliation was reported to occur after the test result was sent to the PCP. Some PCPs described running audits to reconcile test requests with test reports to ensure their patients had attended for testing and the laboratory had reported the results:

'Computerised system flags unreconciled tests and these are reviewed.' (PCP, Manitoba)

If PCPs were particularly concerned about the patient, some reported keeping a separate record of this to ensure tests were performed and results acted on. PCPs described using digital and non-digital formats to do this:

'I also learned to keep a written list of patients needing follow-up so that, if they do not return as expected, I can follow them up.' (PCP, England)

'I manually record tests ordered where I am concerned there might be serious pathology.' (PCP, Northern Ireland)

'All consultations and diagnostic imaging and tests are recorded and reconciled, with the exception of blood tests. If I am concerned about a patient, I message myself in the EMR to confirm tests have been done within a specific time period.' (PCP, Ontario)

Test communication

Significantly fewer UK PCPs reported retaining responsibility for test result communication compared with their non-UK counterparts (73% versus 85%, $P = 0.04$) (Table 2). In the vignettes, UK PCPs also retained responsibility less often for patient follow-up after a test was requested (Table 4). This difference was significant in two vignettes (colorectal cancer vignette 1 [25% versus 45%, $P = 0.02$]) and lung cancer vignette 3 [24% versus 52%, $P = 0.01$]), and marginally significant in another (ovarian cancer vignette 5 [29% versus 45%, $P = 0.05$]) (Table 4).

Some PCPs described how they would

Table 2. Proportion of PCPs in each jurisdiction retaining responsibility for follow-up during the diagnostic process in the four direct questions

PCP retains responsibility for:	UK				Non-UK								P-value ^a
	Wales	Northern Ireland	England	Europe			Canada			Australasia			
				Denmark	Norway	Sweden	Manitoba	Ontario	New South Wales	Victoria	New Zealand		
Follow-up appointments, %	42	52	41	80	89	93	50	43	27	28	29	0.27	
% [95% CI]		44.7 [38.2 to 51.2]					56.7 [36.6 to 75.7]						
Test result reconciliation, %	27	33	23	25	29	69	39	19	53	45	38	0.07	
% [95% CI]		27.2 [22.0 to 32.8]					39.1 [27.5 to 51.4]						
Test result communication, %	77	64	78	72	98	82	89	90	70	73	94	0.04	
% [95% CI]		73.2 [65.0 to 80.7]					85.1 [76.9 to 91.8]						
Follow-up of non-attenders, %	76	71	85	90	93	93	90	91	96	97	96	<0.001	
% [95% CI]		77.7 [69.0 to 85.4]					93.4 [91.3 to 95.3]						

^aData in bold has a significance level of $P \leq 0.05$. CI = confidence interval. PCP = primary care practitioner.

contact patients directly if an abnormal result was potentially serious, or if a patient was more vulnerable:

'Significantly abnormal results will cause me to contact patient, but minor abnormalities aren't routinely followed up, unless patient known to be vulnerable.' (PCP, England)

Some practices had systems in place that enabled administrative teams to assist with the process of contacting patients. For example, in one practice PCPs nominated the time interval in which this should happen:

'I put a recall on the result and mark it urgent (within 24 hours), semi urgent (within 7 days), or non-urgent (within 3-4 weeks). I depend on the administrative assistant to do the recall.' (PCP, Manitoba)

Other PCPs described using 'results tags', or ran audits to check that patients had been reviewed:

'Our admin staff check the results and doctor's comments monthly. Any abnormal results asked to "see or speak to doctor" not been acted on, we send a letter to the patient asking them to contact us.' (PCP, Wales)

There is evidence of PCPs employing a strategy the authors have termed 'double safety netting', in which two methods of follow-up are initiated, often simultaneously, to increase the likelihood of the action being completed. For example, the PCP agrees an action (a telephone call), but at the same time they also request that the patient arranges a follow-up appointment after the test has been performed:

'Normally, a follow-up physician appointment is booked, but I am also asking the patient to phone, that is, doubled safety.' (PCP, Denmark)

'I usually call the patient when the results are available but also tell her at the initial appointment that she is to come in for an appointment within 2 weeks of having the testing done if she does not hear from me.' (PCP, Canada)

Follow-up of non-attenders (DNAs)

Significantly fewer UK PCPs retained responsibility for the follow-up of non-attenders compared with non-UK PCPs (78% versus 93%, $P < 0.001$) (Table 2). Different strategies were used to follow up patients who did not attend appointments.

Table 3. Proportion of PCPs choosing to retain responsibility for patient follow-up when no test is requested, by vignette and jurisdiction

	UK					Non-UK							
	Wales		Northern Ireland	England	Europe		Canada		Australasia		P-value ^a		
					Denmark	Norway	Sweden	Manitoba	Ontario	New South Wales		Victoria	New Zealand
GP retains responsibility for follow-up when no test is requested, %													
Colorectal cancer vignette 1	19	14	29	21	29	35	41	36	19	42	23		
% (95% CI)			21.1 [13.5 to 29.8]					30.6 [24.1 to 37.5]					0.08
Colorectal cancer vignette 2	39	0	42	14	18	80	46	22	25	50	67		
% (95% CI)			22.5 [0.60 to 57.4]					33.7 [19.8 to 48.9]					0.51
Lung cancer vignette 3	44	31	35	60	63	47	53	46	54	47	16		
% (95% CI)			38.9 [30.1 to 48.0]					47.5 [35.4 to 59.7]					0.27
Lung cancer vignette 4	36	31	36	63	42	46	69	61	71	69	35		
% (95% CI)			34.7 [27.0 to 42.8]					57.7 [47.9 to 67.3]					<0.001
Ovarian cancer vignette 5	20	5	38	28	34	31	38	43	36	48	22		
% (95% CI)			20.6 [5.60 to 41.1]					34.7 [29.3 to 40.3]					0.18

^aData in bold has a significance level of P<0.05. CI = confidence interval. PCP = primary care practitioner.

Table 4. Proportion of PCPs choosing to retain responsibility for patient follow-up after a test is requested, by vignette and jurisdiction

	UK					Non-UK							P-value ^a
	Wales	Northern Ireland		England	Europe		Canada			Australasia			
					Denmark	Norway	Sweden	Manitoba	Ontario	New South Wales	Victoria	New Zealand	
GP retains responsibility for follow-up when a test is requested, %													
Colorectal cancer vignette 1	18	24	30	16	70	79	51	48	23	20	57		
% (95% CI)			24.9 (17.7 to 32.8)					44.8 (29.6 to 60.4)				0.02	
Colorectal cancer vignette 2	14	44	24	14	74	82	55	42	24	17	62		
% (95% CI)			25.9 (10.5 to 45.1)					45.7 (27.8 to 64.3)				0.14	
Lung cancer vignette 3	23	29	22	13	77	83	66	60	23	25	69		
% (95% CI)			23.6 (17.6 to 30.2)					51.7 (32.5 to 70.6)				0.01	
Lung cancer vignette 4	50	0	50	17	100	100	72	80	40	29	71		
% (95% CI)			45.4 (15.3 to 77.0)					70.0 (44.1 to 91.0)				0.19	
Ovarian cancer vignette 5	26	30	30	13	66	59	51	57	27	22	73		
% (95% CI)			28.5 (21.2 to 36.4)					45.2 (30.4 to 60.4)				0.05	

^aData in bold has a significance level of P<0.05. CI = confidence interval. PCP = primary care practitioner.

Box 1. Coding themes from the free-text analysis

Follow-up appointments

Titration of retention of responsibility to level of concern
PCP retains responsibility and arranges follow-up themselves at the time of the first consultation
PCP delegates responsibility of arranging follow-up to colleague

Test reconciliation

Audits/software used to monitor test reconciliation
PCP uses non-digital record of patients who require follow-up or tests ordered
PCP uses digital record of patients who require follow-up or tests ordered

Test communication

PCP contacts patient directly if significantly abnormal result, or the patient is vulnerable
PCP delegates (through administrative system) contacting patients about test results
Audits/software used to check that abnormal results have been followed up
Double safety netting (test communication)

Follow-up

Double safety netting (follow-up appointment)
Request for follow-up appointment noted in invoicing software

EMR = electronic medical record. PCP = primary care practitioner

Some PCPs described how they kept a diary of patients they wished to see again. Double safety netting was also used to ensure that patients who miss appointments were followed up. For example, the patient is asked to book a review appointment and a recall is also added to a computer system, so that staff can ensure follow-up takes place:

'I ask the patient to book with reception for a review appointment within a specified time frame (for example, come back in 6 weeks). I add a recall into our software system, to remind myself that they are due to return for results, and I or staff will contact them if they do not attend in the time frame advised.' (PCP, Victoria)

PCPs based in jurisdictions where patients paid for appointments also included patient recall information on the invoice:

'Generally, I tell the patient the time frame, and I note that in the billing information sent to reception.' (PCP, New South Wales)

DISCUSSION

Summary

The authors conducted a secondary analysis of data from an online survey on cancer diagnostics in primary care. The results show substantial variation between jurisdictions in the level that PCPs retained responsibility for follow-up, ranging from 19–97% across jurisdictions and area of follow-up. There was most variation for appointment follow-up and test result

reconciliation across jurisdictions, although UK PCPs retained responsibility significantly less than non-UK PCPs in the other two areas of follow-up: test communication and DNA follow-up.

The accurate, consistent, and timely reconciliation of test results by PCPs, and then the communication of results to the patient, reduces the likelihood of diagnostic error and promotes timely and appropriate follow-up.¹⁸ The authors' results highlight that test reconciliation is inadequately performed, and that test communication is dependent upon test reconciliation. This prevalent potential weakness in the diagnostic pathway, common to all jurisdictions, could leave patients vulnerable to missed opportunities for diagnosis.

Sociodemographic groups associated with delayed presentation to primary care are also more likely to not attend appointments.^{27–30} PCPs reported retaining responsibility more often for DNA follow-up than for appointments, test reconciliation, and test communication, yet significantly fewer UK PCPs report doing this. Structural differences in primary care may enable or prohibit PCP DNA follow-up.³¹ For example, the authors' findings highlight that invoicing is used as an opportunity to formalise DNA follow-up and communicate follow-up intentions in systems with co-payment.

PCPs have developed bespoke, but inconsistent, and often manual solutions to test follow-up. In cases of greatest concern, additional contingencies for result communication are put in place, with, for example, the PCP agreeing to contact the patient while also asking them to contact the surgery for results. This doubling up of safety-netting actions or 'double safety netting' aims to increase the likelihood that the patient would return for follow-up. It could help to identify when tests are performed but not reported back to the PCP, but would fail if a test was not performed because the patient chose not to attend, or the test was not reported back to the surgery and the patient assumed 'no news was good news'.³² Furthermore, responsibility for test communication was often directly delegated to non-clinical staff, and indirectly when patients were asked to contact the surgery for their results. The extent, acceptability, and safety of such strategies are under investigation in the UK.³³

Strengths and limitations

To the authors' knowledge, this is the first study to document the extent to which PCPs retain responsibility for follow-up across

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Ethical approval

The original ICBP3 survey received ethical approval from the NRES Committee South Central, Berkshire. This secondary analysis did not require further ethical approval.

Provenance

Freely submitted; externally peer reviewed.

Competing interests

The authors have declared no competing interests.

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international jurisdictions. The authors used data from a recent large validated international survey of PCPs developed by primary care cancer experts.²³ The main limitations were:

- variable sampling methods between jurisdictions;
- the low survey response rate in some jurisdictions, leading to concerns about the representativeness of the PCP sample;¹⁰
- the uncertainty surrounding the responses about test follow-up in the fourth vignette (lung cancer) (as demonstrated by the wide confidence intervals for the pooled estimates), although the variation in sample sizes was taken into account by the arcsine transformation;
- the reliance on participant recall to document PCP practice, although direct observation would be unfeasible;
- the risk that UK researchers have interpreted non-English free-text responses incorrectly, although the translation and interpretation has been corroborated by international co-authors; and
- the observation that not all PCPs provided free-text comments, which were no substitute for carefully designed and purposively sampled qualitative research.³⁴ However, the free-text responses in this survey contextualise the variability in follow-up identified in the quantitative analysis.

Comparison with existing literature

International differences in primary care cancer investigation,¹⁰ cancer guidelines,²⁴ the centralisation of services, free movement of patients between providers, the existence of patient list systems, and secondary care access have already been elucidated by ICBP3.³¹ These findings add variations in systems for follow-up. Inadequate processes and variation in test follow-up, similar to those highlighted here across international jurisdictions, have been described in the UK.^{15,18,35,36} In the US, Callen *et al* called for urgent action to clarify the responsibility, timing, and process of test notification, integrate information and communication technologies, and to consider the multidisciplinary nature of

patient follow-up, including the patient's role.³⁷ EHR-based triggers have been shown to increase the proportion of symptomatic patients who receive follow-up for suspected cancer,^{38–40} but substantial social and technical challenges exist for the adoption of innovation.^{41,42}

Implications for research and practice

At present, this study shows that primary care relies upon individual practice and practitioner strategies to overcome weaknesses in systems for patient follow-up, despite the availability of information technology and use of the EHR in primary care.³¹ Due to a relatively low level of responsibility retained by PCPs for follow-up in this study, the use of a 'wait-and-see' follow-up strategy may lead to missed diagnostic opportunities.^{3,7} To a large degree, this is modifiable using procedures, information technology, and supportive systems in the EHR, and could also include patient responsibilities.⁴³ Given the great variability in safety-netting practice reported by PCPs across and within jurisdictions, a clear implication for practice is for PCPs to evaluate the effectiveness of their individual approach to safety netting. In particular, PCPs should consider what safety netting means in their context, what led to their approach, which patients they follow up and for what clinical scenario, and to identify factors that may prevent patients from receiving follow-up who may otherwise benefit from it.

At a systems level, research is required to understand the benefits and unintended consequences of automated EHR systems, and to develop and evaluate standardised systems that routinely identify tests and investigations to be requested, performed, and acted upon. At a practitioner level, research is required to understand how, and based on what information, PCPs construct the hierarchies of concern they use to titrate their approach to follow-up, including when PCPs delegate this responsibility to staff and patients. 'Double safety netting' has been described here for the first time and should be explored further, especially in at-risk patient groups with high deprivation scores and comorbidity.⁴⁴ As the workload in primary care is increasing,⁴⁵ research is required to understand how health service reorganisation and new models of access affect strategies for patient follow-up.^{33,46}

REFERENCES

- Singh H, Giardina TD, Meyer AN, *et al*. Types and origins of diagnostic errors in primary care settings. *JAMA Intern Med* 2013; **173**(6): 418–425.
- Willis BH, Beebe H, Lasserson DS. Philosophy of science and the diagnostic process. *Fam Pract* 2013; **30**(5): 501–505.
- Almond SC, Summerton N. Diagnosis in general practice. Test of time. *BMJ* 2009; **338**: b1878.
- Singh H, Schiff GD, Graber ML, *et al*. The global burden of diagnostic errors in primary care. *BMJ Qual Saf* 2017; **26**(6): 484–494.
- National Academies of Sciences, Engineering, and Medicine. *Improving diagnosis in health care*. Washington, DC: National Academies Press, 2015. <https://doi.org/10.17226/21794> [accessed 26 Mar 2018].
- Gandhi TK, Kachalia A, Thomas EJ, *et al*. Missed and delayed diagnoses in the ambulatory setting: a study of closed malpractice claims. *Ann Intern Med* 2006; **145**(7): 488–496.
- Lyratzopoulos G, Vedsted P, Singh H. Understanding missed opportunities for more timely diagnosis of cancer in symptomatic patients after presentation. *Br J Cancer* 2015; **112**: S84–S91.
- Poon EG, Kachalia A, Puopolo AL, *et al*. Cognitive errors and logistical breakdowns contributing to missed and delayed diagnoses of breast and colorectal cancers: a process analysis of closed malpractice claims. *J Gen Intern Med* 2012; **27**(11): 1416–1423.
- Rubin GP, Saunders CL, Abel GA, *et al*. Impact of investigations in general practice on timeliness of referral for patients subsequently diagnosed with cancer: analysis of national primary care audit data. *Br J Cancer* 2015; **112**(4): 676–687.
- Rose PW, Rubin G, Perera-Salazar R, *et al*. Explaining variation in cancer survival between 11 jurisdictions in the International Cancer Benchmarking Partnership: a primary care vignette survey. *BMJ Open* 2015; **5**(5): e007212.
- Buntinx F, Mant D, Van den Bruel A, *et al*. Dealing with low incidence serious diseases in general practice. *Br J Gen Pract* 2011; DOI: <https://doi.org/10.3399/bjgp11X548974>.
- Almond S, Mant D, Thompson M. Diagnostic safety-netting. *Br J Gen Pract* 2009; DOI: <https://doi.org/10.3399/bjgp09X472971>.
- Roland D, Jones C, Neill S, *et al*. Safety netting in healthcare settings: what it means, and for whom? *Arch Dis Child Educ Pract Ed* 2013; **99**(2): 48–53.
- Nicholson BD, Mant D, Bankhead C. Can safety-netting improve cancer detection in patients with vague symptoms? *BMJ* 2016; **355**: i5515.
- Litchfield I, Bentham L, Hill A, *et al*. Routine failures in the process for blood testing and the communication of results to patients in primary care in the UK: a qualitative exploration of patient and provider perspectives. *BMJ Qual Saf* 2015; **24**(11): 681–690.
- Jensen H, Nissen A, Vedsted P. Quality deviations in cancer diagnosis: prevalence and time to diagnosis in general practice. *Br J Gen Pract* 2014; DOI: <https://doi.org/10.3399/bjgp14X677149>.
- Singh H, Sittig DF. Were my diagnosis and treatment correct? No news is not necessarily good news. *J Gen Intern Med* 2014; **29**(8): 1087–1089.
- Litchfield IJ, Bentham LM, Lilford RJ, *et al*. Patient perspectives on test result communication in primary care: a qualitative study. *Br J Gen Pract* 2015; DOI: <https://doi.org/10.3399/bjgp15X683929>.
- Cromme SK, Whitaker KL, Winstanley K, *et al*. Worrying about wasting GP time as a barrier to help-seeking: a community-based, qualitative study. *Br J Gen Pract* 2016. DOI: <https://doi.org/10.3399/bjgp16X685621>.
- Evans J, Chapple A, Salisbury H, *et al*. 'It can't be very important because it comes and goes' — patients' accounts of intermittent symptoms preceding a pancreatic cancer diagnosis: a qualitative study. *BMJ Open* 2014; **4**(2): e004215.
- Htun HW, Elwood JM, Ioannides SJ, *et al*. Investigations and referral for suspected cancer in primary care in New Zealand — a survey linked to the International Cancer Benchmarking Partnership. *Eur J Cancer Care* 2017; **26**(3): e12634.
- Butler J, Foot C, Bomb M, *et al*. The International Cancer Benchmarking Partnership: an international collaboration to inform cancer policy in Australia, Canada, Denmark, Norway, Sweden, and the United Kingdom. *Health Policy* 2013; **112**(1–2): 148–155.
- Rose PW, Hamilton W, Aldersey K, *et al*. Development of a survey instrument to investigate the primary care factors related to differences in cancer diagnosis between international jurisdictions. *BMC Fam Pract* 2014; **15**: 122.
- Nicholson BD, Mant D, Neal RD, *et al*. International variation in adherence to referral guidelines for suspected cancer: a secondary analysis of survey data. *Br J Gen Pract* 2016; DOI: <https://doi.org/10.3399/bjgp16X683449>.
- Nyaga VN, Arbyn M, Aerts M. Metaprop: a Stata command to perform meta-analysis of binomial data. *Arch Public Health* 2014; **72**(1): 39.
- Holton J, Walsh I. *Classic grounded theory: applications with qualitative and quantitative data*. Thousand Oaks, CA: SAGE Publications, 2016.
- Neal RD, Hussain-Gambles M, Allgar VL, *et al*. Reasons for and consequences of missed appointments in general practice in the UK: questionnaire survey and prospective review of medical records. *BMC Fam Pract* 2005; **6**(1): 47.
- Moscrop A, Siskind D, Stevens R. Mental health of young adult patients who do not attend appointments in primary care: a retrospective cohort study. *Fam Pract* 2012; **29**(1): 24–29.
- Forbes LJ, Warburton F, Richards MA, Ramirez AJ. Risk factors for delay in symptomatic presentation: a survey of cancer patients. *Br J Cancer* 2014; **111**(3): 581–588.
- Lyratzopoulos G, Abel GA, Barbieri JM, *et al*. Variation in advanced stage at diagnosis of lung and female breast cancer in an English region 2006–2009. *Br J Cancer* 2012; **106**(6): 1068–1075.
- Brown S, Castelli M, Hunter DJ, *et al*. How might healthcare systems influence speed of cancer diagnosis: a narrative review. *Soc Sci Med* 2014; **116**: 56–63.
- Kwan JL, Cram P. Do not assume that no news is good news: test result management and communication in primary care. *BMJ Qual Saf* 2015; **24**(11): 664–666.
- Litchfield I, Gale N, Burrows M, Greenfield S. Protocol for using mixed methods and process improvement methodologies to explore primary care receptionist work. *BMJ Open* 2016; **6**(11): e013240.
- Garcia J, Evans J, Reshaw M. 'Is there anything else you would like to tell us?' — methodological issues in the use of free-text comments from postal surveys. *Qual Quant* 2004; **38**(2): 113–125.
- Litchfield I, Bentham L, Lilford R, *et al*. Test result communication in primary care: a survey of current practice. *BMJ Qual Saf* 2015; **24**(11): 691–699.
- Litchfield IJ, Bentham LM, Lilford RJ, *et al*. Test result communication in primary care: clinical and office staff perspectives. *Fam Pract* 2014; **31**(5): 592–597.
- Callen JL, Westbrook JL, Georgiou A, Li J. Failure to follow-up test results for ambulatory patients: a systematic review. *J Gen Intern Med* 2012; **27**(10): 1334–1348.
- Murphy DR, Laxmisan A, Reis BA, *et al*. Electronic health record-based triggers to detect potential delays in cancer diagnosis. *BMJ Qual Saf* 2014; **23**(1): 8–16.
- Murphy DR, Thomas EJ, Meyer AN, Singh H. Development and validation of electronic health record-based triggers to detect delays in follow-up of abnormal lung imaging findings. *Radiology* 2015; **277**(1): 81–87.
- Murphy DR, Wu L, Thomas EJ, *et al*. Electronic trigger-based intervention to reduce delays in diagnostic evaluation for cancer: a cluster randomized controlled trial. *J Clin Oncol* 2015; **33**(31): 3560–3567.
- Singh H, Spitzmueller C, Petersen NJ, *et al*. Primary care practitioners' views on test result management in EHR-enabled health systems: a national survey. *J Am Med Inform Assoc* 2013; **20**(4): 727–735.
- Murphy DR, Reis B, Kadiyala H, *et al*. Electronic health record-based messages to primary care providers: valuable information or just noise? *Arch Intern Med* 2012; **172**(3): 283–285.
- Singh H, Giardina TD, Petersen LA, *et al*. Exploring situational awareness in diagnostic errors in primary care. *BMJ Qual Saf* 2012; **21**(1): 30–38.
- Mounce LTA, Price S, Valderas JM, Hamilton W. Comorbid conditions delay diagnosis of colorectal cancer: a cohort study using electronic primary care records. *Br J Cancer* 2017; **116**(12): 1536–1543.
- Hobbs FD, Bankhead C, Mukhtar T, *et al*. Clinical workload in UK primary care: a retrospective analysis of 100 million consultations in England, 2007–14. *Lancet* 2016; **387**(10035): 2323–2330.
- Andersen RS, Vedsted P. Juggling efficiency. An ethnographic study exploring healthcare seeking practices and institutional logics in Danish primary care settings. *Soc Sci Med* 2015; **128**: 239–245.

Appendix 1. International Cancer Benchmarking Partnership Module 3 (ICBP3) survey clinical vignettes

Vignette 1 — colorectal cancer

You are consulted by a 43-year-old woman with a previous diagnosis of diarrhoea-predominant irritable bowel syndrome (IBS) for 10 years, treated with mebeverine 135 mg three times daily (tds) when she is symptomatic. She presents saying her IBS is worse. On further questioning, she has increased colicky abdominal pain every day, but not at night. Her bowel habit is unchanged. She has taken her mebeverine 135mg tds regularly, but it is not helping as much as usual. There are no other gastrointestinal symptoms, and no weight loss. She says her periods are regular (LMP 2 weeks earlier) but not heavy and they last 5 days. No family history of cancer.

Vignette 2 — colorectal cancer

A 68-year-old man comes to see you. He has no relevant past medical history of note, and is on no medication. He complains of loose stools twice each day most days for the past 4 weeks. He has had no recent travel or contact with illness. There is no other relevant clinical history, including normal appetite and no weight loss. Examination, including rectal exam, is normal.

Vignette 3 — lung cancer

A 68-year-old female consults you. She is mildly hypertensive, well controlled (BP 140/90) on ramipril 5 mg once daily for 2 years. She smoked 20 cigarettes a day for 30 years, but stopped 2 years ago. She has coughed most mornings for at least 2 years, but for the last 3 weeks, following an upper respiratory tract infection, she has coughed more, and the cough persists throughout the day. She is coughing up some sputum but there is no haemoptysis. She has no other chest symptoms and no weight loss. Ear, nose, and throat (ENT/OTL) and chest examination is normal.

Vignette 4 — lung cancer

You are consulted by a 62-year-old male smoker with chronic obstructive pulmonary disease (COPD) diagnosed by spirometry 2 years previously. He has smoked 20 cigarettes a day for over 40 years. His current medication is tiotropium inhaler 1 puff daily and salbutamol inhaler for use as required. There is no other relevant past medical history. He presents with a 1-week history of an upper respiratory tract infection with increased sputum production and increased use of his inhaler. On examination he is not cyanosed, and has a normal respiratory rate, but he has some crepitations at the left base and some upper lobe wheeze (rhonchi) bilaterally.

Vignette 5 — ovarian cancer

A 53-year-old woman, whose last period was 6 months ago, presents to you with a history of new colicky lower abdominal pain R>L for 3 weeks. She has no vaginal or urinary symptoms. She has had the same sexual partner for 20 years. She has had no change in the frequency or consistency of her stools. She is a frequent attender, often with complaints that remain undiagnosed. Abdominal examination is normal.